Palliative and Supportive Care

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Creation of a tool to evaluate supportive care

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Abstract

Rational. The absence of a specific tool to evaluate the impact of supportive care in general and socioesthetics (SE) in particular is undoubtedly at the origin of the lack of published research based on scientific standards.

Objective. We developed a supportive-care, patient-reported outcome questionnaire using the multistep methods, following COSMIN recommendations.

Methods. The Patient Centricity Questionnaire (PCQ) was developed using the standardized methodology for designing patient-reported outcome (PRO) questionnaires according to the following steps: elaboration of the questionnaire, measurement properties of the questionnaire, internal and external validation, test–retest validation and translation, cross-cultural adaptation, and cognitive debriefing. A multidisciplinary work group was designed including professionals, such as physicians, public health experts, sociologists, supportive-care experts, and socioestheticians.

Results. Our questionnaire includes 11 items. It is scored by adding each Visual Analogue Scale [VAS], making it range from 0 to 110, with a higher benefit when the score is higher. The Cronbach's α coefficient is 0.88 for the entire questionnaire. As the questionnaire is a reflection of the patient's feelings, it is quite natural that the name "Patient Centricity Questionnaire" (PCQ) was retained and validated by the Scientific Committee. The PCQ correlated negatively and moderately with the Perceived Stress Scale [PSS], positively and moderately with the mental dimension of the Short Form-12, and poorly with the Well Beng 12 [WB12], the physical dimension of the SF-12, and the satisfaction VAS.

Conclusion. Constructed according to the recommendations, the PCQ meets the prerequisite for this type of questionnaire. Its short format and simplicity of use allow it to be used by a large number of people. The PCQ is a simple, reliable, easy-to-use, and validated tool for research teams, making it possible for randomized studies to prove the impact of supportive care in general and SE in particular, on the patient's quality of life.

Introduction

Supportive care is defined as "all the care and support required by patients throughout their illness in conjunction with oncological or oncohematological treatments" and aims to ensure the best possible quality of life for patients on a physical, psychological, and social level, taking the diversity of their needs and those of their family and friends into account, regardless of their place of care (Krakowski, 2006).

A recent international study involving more than 11,000 individuals in five countries (France, China, Russia, the USA, and Brazil) assessed the use of supportive cancer care (SCC). 63% of French respondents, 73% of American respondents, 84% of Brazilian respondents, 64% of Russian respondents, and 86% of Chinese respondents who had received chemotherapy or radiotherapy acknowledged that they had used supportive care (Buiret et al., 2022).

Various SCC treatments, such as corrective makeup, massages, facial care, body care, and clothing advice, which are also called "socioesthetics" (SE), beauty treatments, "beauty care (BC)," or "beauty therapy" in some countries, were reported by numerous patients (Russia: 24%, China or Brazil: 60%, USA: 47%, and France: 37%). It can be defined as "a professional practice of aesthetic care for populations suffering from or weakened by an attack on their physical or psychological integrity, or in social distress." Several surveys and qualitative studies have shown a positive clinical impact in patients receiving such BC, in terms of improved self-image and self-esteem, reduced anxiety, as well as improved sex life and treatment tolerance.

Thus, SE (also called "onco-aesthetics" in oncology) has largely found its place in supportive care, as, throughout the treatment process, it helps to address the undesirable effects of treatments on the skin and skin appendages, situations of stress and anxiety, and disturbances

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in body image. Recently, even antalgic effects for male and female cancer patients were proven for the first time (Buiret et al., 2021).

Although patients and medical and nursing teams who refer their patients agree on the benefits of this practice, scientific proof of the improvements has not yet been demonstrated. For instance, its benefits on the quality of life of cancer survivors have not been assessed thus far. Randomized controlled trials dedicated to BC and patients' body image are needed in order to develop practice guidelines, as well as define necessary resources and standardized procedures, adequate timing, and duration of supportive measures so as to bring meaningful early improvements to patients' quality of life and thereby sustain long-term impact (Saghatchian et al., 2021).

The absence of a specific tool to evaluate the impact of SE as a rendered medical service is undoubtedly at the origin of the lack of studies based on scientific standards.

Methods

We developed this supportive-care, patient-reported outcome (PRO) using multistep methods following COSMIN recommendations (Mokkink et al., 2018). This project obtained a favorable opinion on September 11, 2019 from the Ethics Committee of the CHU La Pitié Salpêtriere, Paris (CCP Ile de France 6-2019-A00204-53) and was conducted according to the Declaration of Helsinki. According to French regulations for this type of research (Reference Methodology 003), no written informed consent had to be obtained from participating patients, and an information and non-objection note was given to them.

A standard methodology for the creation of a PRO was used, and a multidisciplinary work group of experts (professionals, such as physicians, public health experts, sociologists, supportive-care experts, and socioestheticians) was created.

The questionnaire followed the recommendations proposed by Seidenberg et al. and Leidy et al. for the development of a self-report questionnaire (Seidenberg et al., 1994).

The same group of experts reached a consensus on how to respond. The choice was made to use a numerical visual scale ranging from 0 for "No, not at all" to 10 for "Yes, always."

To avoid missing data as much as possible, respondents had the option of not expressing themselves if they were not concerned by placing the cursor on zero.

To avoid any confusion regarding timing, all questions began with "currently."

The diversity of the recruiting centers ensured broad recruitment and a consistent diversity of patients in terms of pathologies, geographical location, age, and sociological status. The participating subjects, aged at least 18 years, had to have received supportive care, SE in this case.

The construction of this questionnaire followed several steps: elaboration of the questionnaire, measurement properties of the questionnaire, internal and external validation, test–retest validation and translation, cross-cultural adaptation, and cognitive debriefing.

Step 1: Elaboration of the questionnaire

We conducted a literature search on PubMed to identify already published questionnaires or scoring systems related to SE. We used the algorithm developed by the COSMIN initiative and combined it with the terms "socioesthetic" and the medical subject subheading "aesthetics" as a major topic.

A qualified sociologist conducted a series of 23 individual interviews to elicit expectations and needs of patients in terms of the management of physical appearance, self-esteem, and relaxation, as well as the role of SA in patient support. Using a triangulation approach, we interviewed 10 patients (who were using or had already used SA) (Terwee et al., 2009) as well as 6 SE practitioners, 5 medical professionals advising SE, and 2 members of the SE association. The verbatim data were analyzed using an itinerary method (Desjeux and Zheng, 2002; Carter et al., 2011, 2014; Palazzo et al., 2016). Such methods aim to contextualize and understand the entire process related to an intervention (when was it proposed, why, what it did, and why was it stopped). The result of this analysis was then translated to a series of patients, trying to stay as close as possible to the patients' words verbatim.

Finally, a multidisciplinary work group involving researchers, methodologists, clinicians (medical, paramedical, sociologist, supportive care expert, and SE practitioner) and patients designed a preliminary questionnaire from the qualitative analysis. Each item of the questionnaire was evaluated with a numerical visual scale ranging from 0 for "No, not at all" to 10 for "Yes, always". To avoid missing data as much as possible, the respondents had the option of not expressing themselves if they were not concerned by placing the cursor on zero.

Step 2: Measurement properties of the questionnaire

The measurement properties of the questionnaire were assessed in six steps:

(a) reduction of the number of items,
(b) subscale repartition of items and assessment of factorial validity,
(c) assessment of construct validity,
(d) assessment of reliability,
(e) evaluation of the minimal clinically important difference (MCID), and
(f) transcultural validation in US English.

Reduction of the number of items

We reduced the number of items based on redundancy, which was suspected when the inter-item correlation evaluated by the Spearman correlation coefficient was above 0.8 (Palazzo et al., 2016). We wanted our questionnaire to be useful in all contexts of SE interventions, as these items can differ greatly, as do benefits for patients. Therefore, we decided to exclude only items presenting a major ceiling or floor effect, and we did not exclude items due to low inter-item correlation.

Subscale repartition of items and assessment of factorial validity

Suitability for factorial analysis was assessed by a Kaiser–Meyer–Olkin (KMO) value above 0.8 for all items (Gries et al., 2018). A screen plot with parallel analysis was performed to determine the number of subscales. To allocate each item to a subscale, exploratory factor analysis (EFA) with a cluster rotation was performed. Items presenting a factor loading lower than 0.5 or a cross factor loading higher than 0.2 were excluded from the questionnaire (Palazzo et al., 2016). We assessed internal consistency with Cronbach's alpha (Cronbach, 1951) and McDonald's omega coefficients, aiming to have both >0.7 for the entire questionnaire and each subscale (Cerny and Kaiser, 1977). Readability of the final

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questionnaire was assessed with a SMOG index corrected for French (Cronbach, 1951; Humphreys and Montanelli, 1975).

Factorial validity was assessed using a higher-order factor confirmatory analysis. This analysis confirmed that the subscales could be combined into a single score. The model's suitability was assessed using three criteria: the comparative fit index (CFI) above 0.9, the Tucker–Lewis index (TLI) above 0.9, and root mean square error of approximation (RMSEA) under 0.08.

Validity construct

Patients who receive supportive care are confronted with physical and psychological difficulties, and they may also be confronted with stress and a lack of well-being. These impacts motivated and justified the choice of the PSSS (Cohen et al., 1983), SF-12 (Lim and Fisher, 1999), and WBQ12 (Bradley, 1994).

We hypothesized several relationships between the SE score and other constructs. Specifically, there was a moderate negative correlation with the stress evaluated through the Perceived Stress Scale (PSS), a moderate positive correlation with the mental dimension of the SF-12 ($r = 0.5$–0.7) and a low correlation ($r = 0$–0.3) with the physical dimension of the SF-12, the satisfaction visual analog scale (VAS) for SE intervention, and well-being evaluated by the well-being questionnaire (WBQ12).

Reliability

Fifty participants who did not previously answer the questionnaire were asked to complete it once and then again three weeks later. Reliability was measured by the intraclass correlation coefficient (ICC) for agreement and presented on a Bland and Altman plot (Contreras et al., 1999; Dunn et al., 2014).

Evaluation of the MCID

The MCID represents the smallest modification detectable in a clinical setting (Bland and Altman, 1986). It was determined using the standard deviation method and the standard of mean method. Using two methods rendered our results more robust.

All data were analyzed using R software version 3.613 for Windows. The significance level was set at $p < 0.05$.

Table 1. Population description

Gender		
Men	38	14.02%
Women	233	85.98%
Age		
Mean ± SD	56.01	14.1
Treatment pathway		
In treatment	177	65.31%
On a treatment break	12	4.43%
In remission	48	17.71%
Cured	14	5.17%
In convalescence	22	8.12%
Not yet in treatment	7	2.58%
Do not know	5	1.85%
Current working status		
Working full time	21	7.75%
Working part time	21	7.75%
Retired	98	36.16%
On leave from work	119	43.91%

Results

The literature review did not involve the retrieval of specifically developed and validated tools to evaluate SE intervention benefits.

The elaboration of the questionnaire led to the identification of 62 themes that were transformed into questions by the expert group.

From October 2019 to February 2020, 271 patients were involved in the assessment of the measurement properties of the questionnaire. Their mean age was 56 years (±14.1); 233 were women (86%) (Table 1).

Reduction of the number of items

Firstly, 90% or more of respondents answered that they were either not concerned by or on one of the extremes of the VAS (0 or 10). This led to the elimination of 23 items. Among the 39 questions, 20 were formulated in a positive way, and 19 were formulated in a negative way. For the simplicity of scoring purposes, the scientific committee decided to eliminate negative questions. All questions included in the subsequent analysis are presented in Table 2.

The inter-item correlation matrix is presented in Figure 1. High inter-item correlation was presented by Q3 (Currently, I feel like I have a positive outlook.) and Q4 [Currently, I have the feeling that things are going well psychologically (or mentally)], which presented a correlation of 87.7% (95% CI [84.6, 90.11]). Additionally, high inter-item correlation was found for Q5 (Currently, I have the feeling that I have regained my calm.) and Q6 (Currently, I feel at peace.), which presented a correlation of 82.2% (95% CI [77.9, 85.7]). Therefore, Q3 and Q4 were eliminated because they were judged as less direct and more difficult to understand.

Subscale repartition of items and assessment of factorial validity

All KMO scores were above 0.85, which confirmed the compatibility of the items for factorial analysis. The scree plot determined three pertinent dimensions (Figure 2).

The EFA determined the distribution of items in the three subscales. These were related to "Serenity" (3 items), "Resilience" (4 items), and "Autonomy" (4 items). Seven items were eliminated due to a low factor loading (Q1, Q7, Q8, Q13, Q14, Q18, and Q20), of which four also had a high cross factor loading (Q1, Q13, Q14, and Q18) (Table 1). Our shortened questionnaire, therefore, included 11 items. It is scored by adding each VAS, making it range from 0 to 110, with a higher benefit when the score is higher. In our population, the score ranged from 12.50 to 110.00, with a mean of 66.7 (22.3 SD).

The Cronbach's α coefficient (Desjeux and Zheng, 2002) was 0.88 (95% CI [0.86, 0.9]) for the entire questionnaire, 0.9 (95% CI [0.88, 0.92]) for the serenity subscale, 0.9 (95% CI [0.88, 0.92]) for the resilience subscale, and 0.9 (95% CI [0.88, 0.92]) for the autonomy subscale. McDonald's Omega coefficient was 0.87 (95% CI [0.82, 0.9]) for the entire questionnaire, 0.9 (95% CI [0.88, 0.92]) for the serenity subscale, 0.89 (95% CI [0.86, 0.92]) for the resilience subscale, and 0.73 (95% CI [0.66, 0.79]) for the autonomy subscale. This confirmed the high coherence of our score.

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Table 2. Presentation of the questionnaire and EFA

	Question	Autonomy	Serenity	Resilience
Q1	Currently, I feel like I have time for myself.	0.15	0.34	0.11
Q2	Currently, I feel like I'm happy again.	0.15	0.8	-0.14
Q3	Currently, I feel like I have a positive outlook.	0.03	0.89	-0.07
Q4	Currently, I have the feeling that things are going well psychologically (or mentally).			
Q5	Currently, I have the feeling that I have regained my calm.			
Q6	Currently, I feel at peace.	-0.02	0.76	0.11
Q7	Currently, I feel pleasure watching a movie.	0.11	0.37	0.11
Q8	Currently, I have the feeling that I have regained my dignity.	0.49	0.21	0.01
Q9	Currently, I am enjoying taking care of myself.	0.87	-0.09	0.01
Q10	Currently, I feel in tune with myself.	0.6	0.32	0
Q11	Currently, I know how to reflect my best self.	0.77	0.14	-0.08
Q12	Currently, I feel like I'm taking better care of myself.	0.96	-0.22	0.05
Q13	Currently, I feel that I can talk more easily about my problems.	0.16	0.12	0.32
Q14	Currently, I feel reassured.	0	0.3	0.48
Q15	Currently, I feel listened to.	-0.13	0.16	0.66
Q16	Currently, I feel like I am actively involved in the management of my care.	-0.1	0.06	0.67
Q17	Currently, I feel like I've learned to take better care of myself.	0.17	-0.19	0.64
Q18	Currently, I feel like I can do the things I want.	0.13	0.41	0.25
Q19	Currently, I feel like I am motivated to fight against my illness.	-0.08	0.02	0.59
Q20	Currently, I feel capable of taking on the efforts of daily life.	0.45	0.19	0.02

Questions in red were eliminated due to redundancy regarding questions 5 and 6, and factor loading for other questions. Factor loadings for each dimension are colored according to the factor where the item has been attributed. The questionnaire is presented in its final transcultural validated form for questions retained in its final form, and other questions were translated from French by the authors.

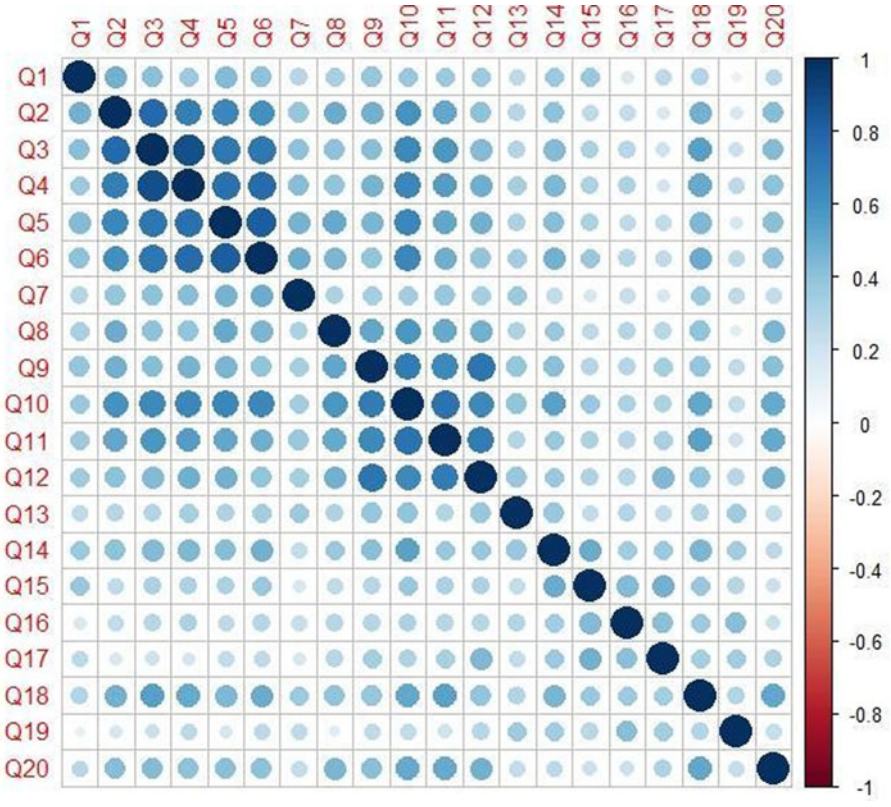


Fig. 1. Interitem correlation matrix.

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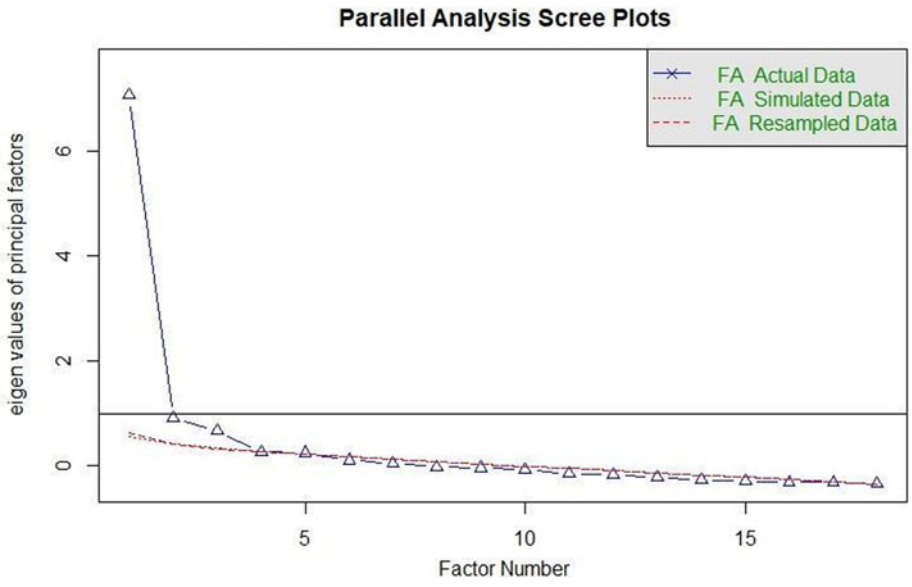


Fig. 2. Screen plot. The number of factors is determined by comparing resampled data and actual data, keeping dimensions where actual data are greater than resampled data.

The readability of the questionnaire was considered excellent (SMOG = 4.73).

The CFA diagram is presented in Figure 3. The TLI was 0.908 and the CFI was 0.931, but the RMSEA was slightly above 0.08 (0.099). The poorer fit indicated by the RMSEA might have been due to the low number of items, as the RMSEA tends to be poorer in this situation (Kenny and McCoach, 2003).

Validity construct

The 11-item questionnaire correlated negatively and moderately with the PSS −0.561 (95% CI [−0.637, −0.473]), positively and moderately with the mental dimension of the SF-12 (95% CI 0.551 [0.459, 0.631]), and poorly with the WB12 0.249 (95% CI [0.133, 0.358]), the physical dimension of the SF-12 0.372 (95% CI [0.261, 0.473]), and the satisfaction EVA 0.163 (95% CI [0.044, 0.277]).

The MCID according to the standard deviation method was 11.1.

Reliability

Thirty-nine individuals participated in the test–retest analysis, of whom 23 did not present any event between the two tests. The ICC was 0.985 (95% CI [0.453, 0.997]), indicating good reliability. The Bland and Altman diagram (Figure 4) showed that the difference between the two answers did not depend on the mean.

None of the patients declared any event (personal, medical, and professional) that could have interfered.

The final cross-culturally adapted questionnaire is presented in Table 2.

Transcultural validation in US English

An American English version of the questionnaire was developed by translation and transcultural validation according to the ISPOR task force recommendation (Wild et al., 2005).

Thus, we obtained one version that is conceptually equivalent to the original: comparable across languages, culturally relevant to the context of the target country, and easily understood by the people to whom the translated instrument is administered

The cognitive debriefing did not result in any major changes of the wording of the questions. Some questions were changed to be clearer or easier to understand by reforming sentences and changing word order. For example, the item "Currently, I feel like I'm taking better care of myself" was preferred over "Currently, I enjoy taking care of myself" in order to take the notion of the patient's feelings into account.

Name of the tool

The questionnaire thus constructed is a reflection of the patient's feelings, and it is quite natural that the name "Patient Centricity

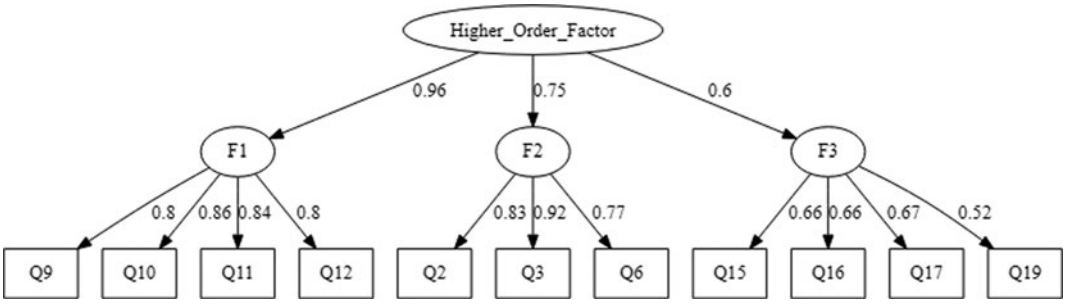


Fig. 3. CFA diagram. The diagram presents factor loading on each subscale. F1 presents autonomy, F2 presents serenity, and F3 presents resilience.

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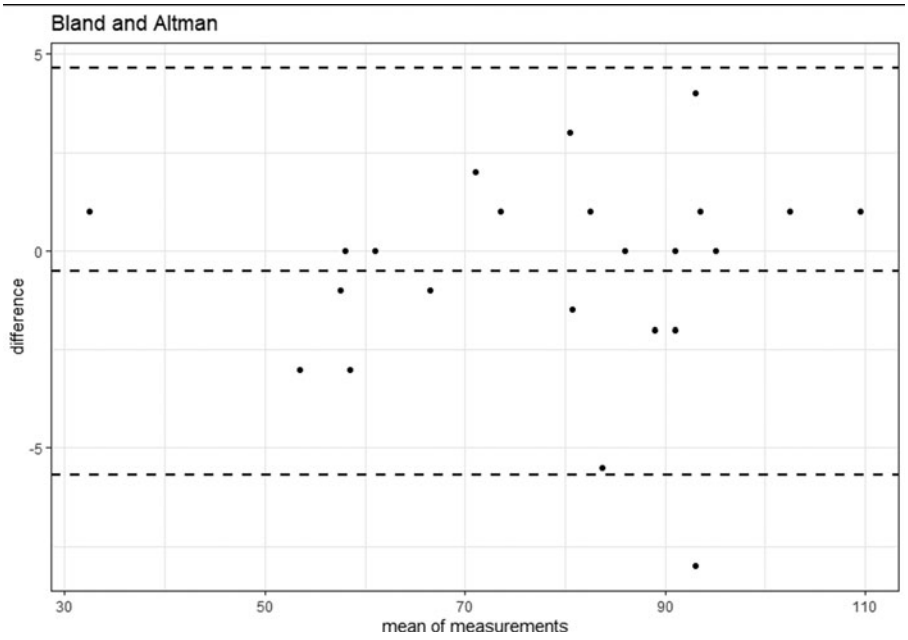


Fig. 4. Bland and Altman diagram. Each dot represents one test–retest patient.

Questionnaire" (PCQ) was retained and validated by the Scientific Committee.

Discussion

We have developed an instrument with good internal and external validity to measure the impact of SE on the quality of life.

Interest in instruments for measuring patients' feelings through the so-called quality of life questionnaires in clinical trials has developed rapidly in the context of the consideration of PROs (Bland and Altman, 1986; Weir, 2005; Saghatchian et al., 2021).

At the end of the 2000s, both the US) and European drug regulatory agencies published recommendations for the development of PRO measures in clinical trials.

We know that nonspecific questionnaires (SF12: Bradley, 1994 or EQ5D: Balieva et al., 2017 among the most used) exist, but if they are of major interest to allow comparison between two exposed populations, they are often not sensitive enough to assess specific domains.

Many specific questionnaires have been created to develop tools that are more sensitive to change. This is the case in cancerology, where specific questionnaires for oncology were created to begin with. In a second phase, specific questionnaires for certain cancers were created in order to understand the impact of a treatment on patients more thoroughly.

This is also the case in dermatology, where generic questionnaires, such as the DLQI (Finlay and Khan, 1994) or the SkinIndex (Chren et al., 1996), are widely used to compare skin diseases between them, but where specific tools have also recently been published for common dermatoses, such as acne or psoriasis (Ezzedine et al., 2020; Dréno et al., 2021), or less frequent ones, such as vitiligo, ichthyosis, or hemangioma (Dufresne et al., 2013; Boccara et al., 2015; Salzes et al., 2016).

Saghatchian pointed out (Saghatchian et al., 2021) that no study had formally demonstrated the improvement in the quality of life by SA, recognizing that studies regarding this approach are difficult to implement according to scientific standards, as no specific tools exist to measure the impact of SA.

It was, therefore, important to create a specific tool to objectively and reproducibly evaluate supportive care in general and ADT in particular.

The PCQ is a short questionnaire that has been constructed according to recommendations and meets the prerequisite for this type of questionnaire.

Its short format (11 questions) and simplicity of use allow it to be used by a large number of people.

This questionnaire provides an answer by making a simple, reliable, easy-to-use, and validated tool available to research teams. It makes "randomized studies (…) to prove the impact of SE on quality of life." possible (Buiret et al., 2021).

Due to the lack of references in literature, SE has recently been classified as wellness care, not supportive care, by the French National Cancer Institute (INCa).

The INCa is the French government agency for health and scientific expertise in cancer, responsible for coordinating actions in the fight against cancer.

The fact that it is placed under the supervision of both the Minister of Health and the Ministry of Research makes it an institution with a central role. It is the equivalent of the National Cancer Institute (NCI) in the USA.

This new tool should help to reconsider this classification. The questionnaire has been validated in the context of SE, but its construction allows us to speculate that it could also be a tool for evaluating various support care services offered to patients as part of their treatment.

The Cronbach's α coefficient found was of good quality since it was close to 0.9 for both the questionnaire as a whole and for its dimensions.

This coefficient is comparable to those found for other questionnaires widely used in many studies, which were used for external validity: the evidence of internal consistency of the revised SF-12 was considered sufficient (Cronbach's α coefficient of 0.72–0.89) (Resnick and Parker, 2001), for the WBQ 12, the internal consistency, measured by Cronbach's α coefficient, was 0.86 (Watrowski and Rohde, 2014), and for the PSS, several studies carried out in the general population in various countries showed

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that Cronbach's α coefficient was between 0.75 and 0.91. (Yokokura et al., 2017).

The PCQ is currently available for free in French, US English, Brazilian, Portuguese, and Italian (Supplementary material).

Terms of use are available from the Fondation L'Oréal (sylviane.balustre@loreal.com) or from the corresponding author.

The questionnaire form can be accessed by scanning the QR code:



Data availability statement. All data are available upon request.

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Author Contributions. C.T. wrote the protocol and its appendices, performed the statistical analysis, and wrote the publication. D.G., G.B., C.G., M.S., and I.K. validated the protocol, recruited the patients, and co-authored the publication. All authors approved the final version to be published.

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Conflict of interest. There are no conflicts of interest to declare.

Patient consent to participate. An information note respecting French legislation was proposed. This note was validated by the ethics committee.

Ethics approval. This project obtained a favorable opinion on September 11, 2019 from the Ethics Committee of the CHU La Pitié Salpêtriere, Paris (CCP Ile de France 6- 2019-A00204-53) and was conducted according to the Declaration of Helsinki and according to French regulations for this type of research (Reference Methodology 003).

References

Balieva F, Kupfer J, Lien L, *et al.* (2017) The burden of common skin diseases assessed with the EQ5D™: A European multicentre study in 13 countries. *British Journal of Dermatology* **176**, 1170–1178.

Bland JM and Altman DG (1986) Statistical methods for assessing agreement between two methods of clinical measurement. *The Lancet* **1**, 307–310.

Boccara O, Meni C, Leaute-Labreze C, *et al.* (2015) Haemangioma family burden: Creation of a specific questionnaire. *Acta Dermato-Venereologica* **95**, 78–82.

Bradley C and Gamsu DS (1994) Guidelines for encouraging psychological well-being: report of a Working Group of the World Health Organization Regional Office for Europe and International Diabetes Federation European Region St Vincent Declaration Action Programme for Diabetes. *Diabetic Medicine* **11**, 510–516. doi: 10.1111/j.1464-5491.1994.tb00316.x.

Buiret G, Sandonato S, Chidiac F, *et al.* (2021) Effets antalgiques de la socio-esthétique chez les patients atteints de cancer [antalgic effects of socio-aesthetics in cancer patients]. *Bulletin du Cancer* **108**, 1030–1035.

Buiret G, Delvigne V, Le Dantec G, *et al.* (2022) Prevalence of radiotherapy, chemotherapy and access to supportive care in cancer in France, Brazil, Russia, the USA & China. *European Journal of Cancer Care*. **16**:e13636. doi: 10.1111/ecc.13636. Epub ahead of print. PMID: 35708175.

Carter N, Bryant-Lukosius D, DiCenso A, *et al.* (2011) The supportive care needs of men with advanced prostate cancer. *Oncology Nursing Forum* **38**, 189–198.

Carter N, Bryant-Lukosius D, DiCenso A, *et al.* (2014) The use of triangulation in qualitative research. *Oncology Nursing Forum* **41**, 545–547.

Cerny BA and Kaiser HF (1977) A study of a measure of sampling adequacy for factor-analytic correlation matrices. *Multivariate Behavioral Research* **12**, 43–47.

Chren MM, Lasek RJ, Quinn LM, *et al.* (1996) Skindex, a quality-of-life measure for patients with skin disease: Reliability, validity, and responsiveness. *Journal of Investigative Dermatology* **107**, 707–713.

Cohen S, Kamarck T and Mermelstein R (1983) A global measure of perceived stress. *Journal of Health and Social Behavior* **24**, 385–396.

Contreras A, García-Alonso R, Echenique M, *et al.* (1999) The SOL formulas for converting SMOG readability scores between health education materials written in spanish, English, and French. *Journal of Health Communication* **4**, 21–29.

Cronbach LJ (1951) Coefficient alpha and the internal structure of tests. *Psychometrika* **16**, 297–334.

Desjeux D and Zheng L (2002) *The itinerary method: comparing intercultural daily life – The case of Guangzhou, China. Consommation & Société.* Available at: https://consommations-et-societes.fr/2002-d-desjeux-zheng-lihua-the-itinerary-method-comparing-intercultural-daily-life-the-case-of-guangzhou-china/.

Dréno B, Khammari A, Seité S, *et al.* (2021) Impact of acne on the daily life of adult patients: Building a self-administered patient questionnaire. *Journal of the European Academy of Dermatology and Venereology* **35**, 1212–1218.

Dufresne H, Hadj-Rabia S, Meni C, *et al.* (2013) Family burden in inherited ichthyosis: Creation of a specific questionnaire. *Orphanet Journal of Rare Diseases* **8**, 28.

Dunn TJ, Baguley T and Brunsden V (2014) From alpha to omega: A practical solution to the pervasive problem of internal consistency estimation. *British Journal of Psychology* **105**, 399–412.

Ezzedine K, Fougerousse AC, Aubert R, *et al.* (2020) Individual burden of psoriasis (I-BOP): Building and validation of a new scoring tool for patients with psoriasis. *Clinical, Cosmetic and Investigational Dermatology* **13**, 325–332.

Finlay AY and Khan GK (1994) Dermatology life quality index (DLQI): A simple practical measure for routine clinical use. *Clinical and Experimental Dermatology* **19**, 210–216.

Gries K, Berry P, Harrington M, *et al.* (2018) Literature review to assemble the evidence for response scales used in patient-reported outcome measures. *Journal of Patient-Reported Outcomes* **2**, 41.

Humphreys LG and Montanelli Jr. RG (1975) An investigation of the parallel analysis criterion for determining the number of common factors. *Multivariate Behavioral Research* **10**, 193–205.

Kenny DA and McCoach DB (2003) Effect of the number of variables on measures of fit in structural equation modeling. *Structural Equation Modeling* **10**, 333.

Krakowski I (2006) Soins de support en oncologie: Concept et état des lieux [supportive care for people affected by cancer: Concept and management]. *Revue du Praticien* **56**, 1989–1996.

Lim LL and Fisher JD (1999) Use of the 12-item short-form (SF-12) health survey in an Australian heart and stroke population. *Quality of Life Research* **8**, 1–8.

Mokkink LB, de Vet HCW, Prinsen CAC, *et al.* (2018) COSMIN risk of bias checklist for systematic reviews of patient-reported outcome measures. *Quality of Life Research* **27**, 1171–1179.

Palazzo C, Klinger E, Dorner V, *et al.* (2016) Barriers to home-based exercise program adherence with chronic low back pain: Patient expectations regarding new technologies. *Annals of Physical and Rehabilitation Medicine* **59**, 107–113.

Resnick B and Parker R (2001) Simplified scoring and psychometrics of the revised 12-item short-form health survey. *Outcomes Management for Nursing Practice* **5**(4), 161–166

Saghatchian M, Lacas B, Charles C, *et al.* (2021) BEAUTY and the breast: Is adjuvant chemotherapy the right time for a beauty boost? Lessons learned from a large randomized controlled trial. *Quality of Life Research* **31**, 723–732. doi: 10.1007/s11136-021-02947-6.

Salzes C, Abadie S, Seneschal J, *et al.* (2016) The vitiligo impact patient scale (VIPs): Development and validation of a vitiligo burden assessment tool. *Journal of Investigative Dermatology* **136**, 52–58.

Seidenberg M, Haltiner A, Taylor MA, *et al.* (1994) Development and validation of a multiple ability self-report questionnaire. *Journal of Clinical and Experimental Neuropsychology* **16**, 93–104.

Terwee CB, Jansma EP, Riphagen II, *et al.* (2009) Development of a methodological PubMed search filter for finding studies on measurement properties of measurement instruments. *Quality of Life Research* **18**, 1115–1123.

Watrowski R and Rohde A (2014) Psychological well-being of gynecologic and obstetric patients: A validation of the 12-item well-being questionnaire (W-BQ12). *Wiener Klinische Wochenschrift* **126**(17–18), 524–531. doi: 10.1007/s00508-014-0569-6.

Weir JP (2005) Quantifying test-retest reliability using the intraclass correlation coefficient and the SEM. *The Journal of Strength and Conditioning Research* **19**, 231–240.

Wild D, Grove A, Martin M, *et al.* (2005) Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: Report of the ISPOR task force for translation and cultural adaptation. *Value in Health* **8**, 94–104.

Yokokura AVCP, Silva AAMD, Fernandes JKB, *et al.* (2017) Perceived stress scale: Confirmatory factor analysis of the PSS14 and PSS10 versions in two samples of pregnant women from the BRISA cohort. *Cadernos de Saúde Pública* **33**(12), e00184615. doi: 10.1590/0102-311X00184615.

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